

We're in this together

“As we all adjust to a strange new world, unsurprisingly, this issue of the newsletter has a coronavirus focus. We have added a coronavirus hub to our website - www.actionpulmonaryfibrosis.org/coronavirus. Here you can find all you need to know about the virus and ways to support yourself and your loved ones whilst in self-isolation. We have also produced six videos, supported by pharmaceutical company Boehringer Ingelheim, which you can access online or on a phone. Just go to our YouTube channel [here](#)



- Mental health
- Nutrition
- How to work Whatsapp and Zoom
- Self-isolation/distancing
- Carers - how to support someone who is self-isolating.

“We are adapting our services, including growing our Support Line which has seen a 68% increase in demand since January 2020 in light of the coronavirus.

“We wish you all the very best during this extremely difficult time. APF will continue to be here to help and support you so please contact us by calling our Support Line on 01223 785 725 or by emailing us at coronavirus@actionpf.org. We look forward to meeting up again when this is over.”

Louise Wright, APF Chief Executive

Mike Bray Fellowship Award leads to exciting discovery



APF is delighted to announce that the research funded through the Mike Bray Fellowship Award has resulted in a breakthrough for idiopathic pulmonary fibrosis patients and their families.

Researchers have discovered parts of the DNA that put some people at higher risk of IPF. The team compared the DNA of 4,000 people with IPF to 20,000 people without. In total they investigated over 10 million changes in the DNA and found that people with IPF were more likely to have changes in three genes that have not previously been known to be involved with the disease. These genes suggest biological pathways which crucially could be targets for new drugs.

One of the genes lies in a pathway that has recently been shown to promote fibrosis in the lungs. Drugs are being developed that can target this pathway and might benefit patients. The other two genes highlight pathways not previously investigated for IPF but which may drive development of new treatments in the future.

APF Research Fellow at the University of Leicester Dr Richard Allen, pictured, said: “These are really exciting discoveries. Hopefully this research will help in the development of treatments which are desperately needed for this devastating disease.”



Welcome

Well, what a strange and unsettling time we are in. There is currently only one topic of conversation – coronavirus – and the world has changed overnight. Understandably, support group meetings are on hold for the time being but please let us know how you are keeping connected and supporting each other. During this very difficult time, I want to look to the future and introduce you to two new members of our support team. Gillian Trippner joins us as Regional Support Co-ordinator for the south and Jo Ruck as RSC for the north.

They will be working to expand the support group network and be offering more support to existing groups to help them reach even more people with pulmonary fibrosis. They'll also be helping all groups to raise awareness locally. You told us that you would value help to organise peer learning and development days and Gillian and Jo will be very involved in those projects.

Already we are seeing the benefit of closer working through the 'virtual' meetings we've hosted for support group leaders - sharing ideas, news and having a bit of fun and encouragement along the way in these very strange times. We look forward to a time when we can meet together in person; until then, stay safe.

Debra Chand, National Support Manager



New co-ordinators join the team

As the number of support groups continues to grow, APF is pleased to announce the appointment of two Regional Support Co-ordinators (RSC).

Gillian Trippner worked for the health service for many years, originally training as a nurse. Recently she has been working in the voluntary sector, setting up a social prescribing service, carer support services and helping voluntary groups bid for projects that improve health and wellbeing. Gillian says: "I am really looking forward to my new role and hope to make a real difference to people who have pulmonary fibrosis, their family, carers and friends."



Joanna Ruck is a physiotherapist with many years' experience working with patients with breathing problems. She helped set up the Derby PF Support Group and says: "I look forward to working with you all to develop and expand our support networks so that no-one living with pulmonary fibrosis has to feel alone and everyone has access to good quality support, wherever they live."

Self-isolating with APF Chair Steve Jones

"I lived with IPF for eight years before having a single lung transplant four years ago. I have to take anti-rejection drugs, which means that I have a weak immune system and am at high risk of coronavirus.

"Because of this, my wife Hilary and I started self-isolating in early March, when there were only about 100 cases in the UK. We'd seen what was happening in other countries and didn't want to take any chances.

"One positive is that I'm enjoying being at home and spending more time with Hilary. I used to travel a lot for APF in the UK and Europe, but that has stopped.

I try to keep to a routine. I spend part of the day working for APF, including conference calls with Louise, our Chief Executive. I am reading more and getting little jobs done around the house.

"It's important to keep in touch with friends and relatives. We frequently speak with family and have re-established contact with old friends – some of whom we've not seen for years. Just pick up the phone – your friends will be really pleased to hear from you! You can use WhatsApp and Zoom but a phone call is just as good.

"We are strict about self-isolating and have not left the house or been nearer than two metres to another person for five weeks. We are also vigilant about hygiene and leave deliveries on one side for a day or two before touching them. We carefully wipe all packaging with disinfectant before putting them away. Research shows coronavirus can live for three days on plastic or metal but only about one day on cardboard and paper. Our local shop and volunteers who deliver groceries to our door have been wonderful.

"Don't be shy about asking for help from others – friends, neighbours and local charities are there for you and want to help."

"The biggest drawback is that we cannot see our four grand-children – all under the age of three. We used to meet them a lot but now we can only talk to them by WhatsApp. They find it strange but they know it's because of 'the bug'. Let's hope this doesn't last too long – and they don't forget who we are!"



Steve and Hilary enjoy a last walk round the village before self-isolation

Support Group Round Up

In the spirit of not-so-splendid isolation, Support Groups have put their meetings on hold for a while, but here's our usual roundup of inspiring activity ready for when we get back to normal. Do let us know how you are keeping connected and supporting each other – both patients and carers. We know that you will all rise to the occasion!



We are delighted to report that the **Princess Alexandra Hospital Support Group** recently launched at Harlow Fire Station in Essex to become the 76th and newest group. Consultant Mr Muhammad Anwar gave a presentation, Respiratory Clinical Specialist Nurse Ruby Varghese and colleagues made everyone very welcome, and Steve Jones and Debra Chand joined in from APF. The group will meet every two months once it is possible to do so. Contact Ruby on ruby.varghese@nhs.net or 01279 444455 to find out more.

The very active **Exeter Support Group** now has an off-shoot group, EPIC PF - Exeter Patients In Collaboration for PF Research. The new group operates in conjunction with the University's medical school, advising on and facilitating patient participation in research projects into IPF treatment and early diagnosis. It is very ably organised by lead researcher at the University Dr Chris Scotton, research team member Dr Anna Duckworth (pictured), and the clinical team at the Royal Devon and Exeter Hospital led by Dr Michael Gibbons and Sarah Lines, ILD Nurse Specialist.



The prestigious British Citizen Awards recognise and reward exceptional endeavour, highlighting the contribution made by individuals to their fellow citizens and to their communities. Two founding members of the **Bolton Support Group** have been recognised for their outstanding services in promoting awareness of idiopathic pulmonary fibrosis (IPF) in their communities and with the medical profession. Sadly, the recipients John Latham (former secretary) and Kenneth Ruscoe (former treasurer), have passed away but they leave a wonderful and lasting legacy behind.

Over the past eighteen months, Northumbria Healthcare Trust has organised a series of information days for people suffering from Interstitial Lung Disease and their carers, the most recent being at Wansbeck General Hospital, Ashington. Middlesbrough based **PF Support Group Tees** welcomed the events, and a bus full of members attended the day in Hexham last year. The events help new patients and carers get the information they need and have also proved a useful source of members for the regional support groups.

Help the Support Line grow when it's needed most

The APF Support Line offers information and advice on a wide range of topics from benefits to oxygen and, most recently, living with PF during the coronavirus pandemic. Run by our Senior Nurse, Lucy, the Support Line offers a listening ear to patients, carers and families.



www.justgiving.com/campaign/apfcoronavirus

Yvette called following her PF diagnosis and says, "I found Lucy to be very calming. She explained everything so carefully and thoroughly, answered my questions and put things into perspective. I came away from the call feeling much better and satisfied that I had some answers."

Yvette recently contacted Lucy again for advice on the coronavirus outbreak and says, "It's really reassuring to know the Support Line is there whenever I need it – I have the number saved!"

Our Support Line is needed now more than ever, and we have seen a significant increase in calls from patients and family members wanting relevant, up-to-date information and advice about self-shielding and keeping well throughout this uncertain time. We need to continue to be there for patients and families today, tomorrow and in the future. But we can't do it alone.

If you would like to help us grow our vital work such as the Support Line during these challenging times, please visit www.justgiving.com/campaign/apfcoronavirus or complete the form below. Together, we can ensure nobody has to face PF alone.

Please return to: Freepost ACTION FOR PULMONARY FIBROSIS (no need to include other address details)

Name _____ Address _____

_____ Post code _____

Email _____ Phone _____

I would like to donate: £10 £20 Other amount _____

Please Gift Aid my donation of £___ and any donations I make in future or have made in the past four years to APF.

I am a UK taxpayer and understand that if I pay less Income Tax and/or Capital Gains Tax in the current tax year than the amount of Gift Aid claimed on all my donations it is my responsibility to pay any difference. I understand the charity will reclaim 25p of tax on every £1 that I have donated. Please notify the charity if you wish to cancel this declaration, change your name or home address, no longer pay sufficient tax on your income and/or capital gains. If you pay Income Tax at the higher or additional rate and want to receive the additional tax relief due to you, you must include all your Gift Aid donations on your Self-Assessment tax return or ask HMRC to adjust your tax code. Gift Aid is reclaimed by the charity from the tax you pay for the current tax year. Your address is needed to identify you as a current UK taxpayer.

I would like to make my donation by BACS

Please quote your name as the reference and use the details below:

Account Name: Action for Pulmonary Fibrosis Sort-code: 40-52-40 Account number: 00023412

I would like to make my donation by cheque Please make cheques payable to Action for Pulmonary Fibrosis

I would like to sign up to receive APF's newsletter by email by post

You can opt out at any time by emailing optout@actionpf.org

Living with pulmonary fibrosis – exercise



Regular exercise is important for both our physical and mental health. It builds muscle strength, improves sleep and helps you to stay a healthy weight. Just as importantly, it can help your mental wellbeing and reduce stress.

Of course exercise can be difficult when you are breathless and, if you are not used to being active, the idea can seem daunting. However, even simple exercises make a big difference to your wellbeing and can improve your quality of life.

The key is to make the exercise regular rather than strenuous. Three or four times a week will maintain the benefits you are gaining and help it become part of your routine.

Coronavirus has limited many opportunities for exercise. Going to a pulmonary rehab session or for a walk with friends are both off the agenda. People with PF are classed as extremely vulnerable, so outdoor exercise beyond your home is not recommended. Here are some ideas for things you *can* do to keep your body moving.

- Build exercise into your normal daily routine and try to keep moving around the house. Housework and odd jobs will keep you active
- Going up and down the stairs, if you are able to, is a great way to keep fit. Why not set yourself a target of steps each day? If the stairs are too much of a challenge why not walk around the room when you're on the phone or just get out of your chair every hour to stretch your legs?
- Gardening is a great way to stay active. If you have a garden or an outdoor space that does not bring you into contact with anyone outside your household, now is the perfect time to start planting. Everything from compost and plant pots to seeds and plants can be purchased online. Why not call your local garden centre or nursery – they may deliver?
- There are lots of exercises popping up on YouTube at the moment and the NHS website has some useful chair-based exercises to try – www.nhs.uk/live-well/exercise/sitting-exercises
- Have a look at the Irish Lung Fibrosis Association exercise video on YouTube – youtube.com and search ILFA Exercise Video. It is specially-designed for PF patients
- The British Lung Foundation also has a series of videos to help you exercise at home – www.blf.org.uk/exercise-video. And of course you can check out the APF video on YouTube [here](#)



Raising awareness with GPs

One of APF's key aims is to raise awareness of pulmonary fibrosis with the medical profession, particularly GPs. Our trustee Howard Almond, pictured above, did just that recently in *The Lancet*, one of the world's most respected medical journals. Here is an edited version of the article which you can see in full [here](#)

"I lived in Austria for a long time but moved back to the UK in 2003 to become my mum's main carer, who had dementia. One day I walked the steep climb to Tintagel Castle in Cornwall and could hardly breathe. I thought I just needed to exercise more, but then developed a persistent cough. My GP heard crackles in my chest and referred me to a respiratory consultant. After a CT scan I was told that I could have idiopathic pulmonary fibrosis (IPF) which I had never heard of. A lung biopsy confirmed the diagnosis.

"One of the best things I did was start 'singing for breathing' classes. In just a couple of months, my forced vital capacity reading went from 70% to 95%! It is truly amazing how learning to breathe properly can help. My lung capacity decreased to 80% while my singing coach was away which shows how much of an impact it had. I have also learned how to recover from breathlessness when out walking.

"My involvement with APF came after I attended an information day and met trustees who spoke about research, support groups, and the lobbying they were doing on behalf of patients. I expressed an interest in helping and was invited to join the board of trustees. There are now over 75 support groups in the UK—something I am immensely proud of. Attending a support group was one of the best decisions I've made, meeting others in the same position all with different methods of coping. I run a small group in Plymouth, and I am about to set up another in Torbay.

"Early in 2019 I had a bit of a crisis. I couldn't walk far and was getting very out of breath doing the simplest of tasks. I was convinced the IPF was progressing rapidly. I was eventually diagnosed with a pulmonary embolism and it took me three months to feel better again. My advice is don't assume that a deterioration in your condition is just progression of the disease.

"Now I am careful not to overstretch myself. I plan ahead and keep my heart rate and exercise at a suitable level. I do remember my time walking without restrictions in the mountains in Austria: how I would love to be able to do that now!

"Essentially, it all comes down to pacing yourself and not expecting miracles. I am constantly aware of the illness—aware of every breath I take. But while my health might have deteriorated I am still able to live a normal life."

Fundraising for the future

We are continuing to support patients and families as they self-shield and self-isolate. This work couldn't happen without the help of our fantastic fundraisers who are adapting their challenges and events to continue raising funds. Here are some inspiring stories and ideas on how you can support APF during these challenging times. You can also donate to the APF Coronavirus Appeal at www.justgiving.com/campaign/apfcoronavirus or email fundraising@actionpf.org for further information

Celebration donations

Hannah and fiancé Ryan were keen to use their March wedding as an opportunity to raise funds for APF. Ryan's dad, Ray, sadly died from PF in October. £200 was raised on the day, on top of funds already raised with a 5k fun run.

Hannah told us, "The family decided to support APF after Ray got diagnosed. I feel so honoured to have known him for the few years I did; he was a wonderful, gentle spirit."

If a wedding isn't in the offing, you can also 'donate your birthday'. Visit www.actionpulmonaryfibrosis.org/fundraising for more information on how you can set up your own birthday fundraiser for APF, or email fundraising@actionpf.org for support with your plans.



Local Landmarks

APF's 25 fantastic fundraising runners were disappointed to learn that the London Landmarks Half-marathon had to be cancelled, but the organisers came up with a novel idea to keep people motivated. The Local Landmarks Challenge is an alternative solo challenge that encourages everyone to run around their local landmarks.

Sam Wilkinson is one of those who took this up, running round his own local landmarks in Northamptonshire. Sam's father-in-law has PF and recently received a lung transplant. "The work that APF do is incredible in supporting families and raising awareness," said Sam, whose run raised over £700.



Three Peaks Challenge

Callum Harrison's grandfather was diagnosed with IPF in 2016 and he persuaded friends to join him on the challenging Yorkshire Three Peaks Challenge to raise funds for APF. After nine hours battling through rain, wind and hail they summited two of the peaks.

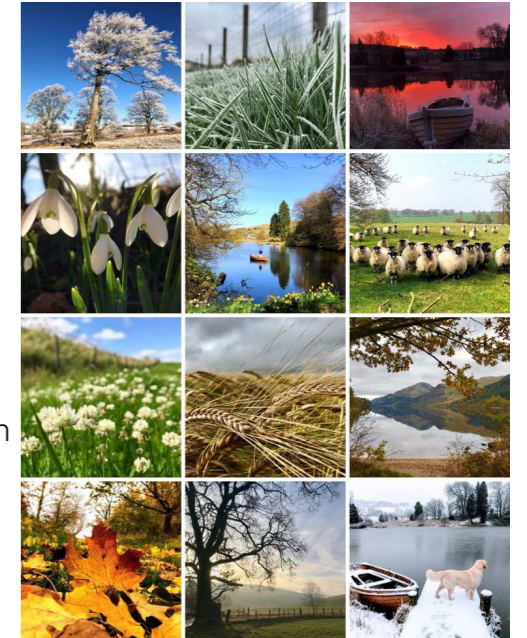
Not to be deterred Callum went back the next day to make his way up the final summit, raising £755 for APF. "This is a wonderful charity so if you want to challenge yourself physically and mentally do something great that helps in the fight against this incurable disease." Thank you Callum and friends!



Weather Watchers' success

Jackie Selcraig and her friend Sam became BBC Weather Watchers in 2019, uploading photos for local and national weather bulletins. They then had the fantastic idea of using twelve of the televised snaps to publish a fundraising calendar for APF. Jackie's 82-year-old dad Alasdair was diagnosed with IPF in 2015. "Dad now needs oxygen when he's out and about and he's struggling with most aspects of his life, but he's got plenty of family support".

The first 100 calendars sold immediately with a further batch printed to meet demand. Endorsement by BBC weather presenter Judith Ralston, and an interview on BBC Radio Scotland, helped Jackie and Sam to raise awareness and an incredible £2,600.



Great Manchester Run - new date!

The GMR now has a new date - Sunday 6 September - and we need your help! You can sign up now for one of our charity places on the 10k or half marathon run. Email fundraising@actionpf.org for details.



Fundraiser of the Year Award



To recognise their enormous efforts we launched our first Fundraiser of the Year Award in 2019. Ten nominees were shortlisted and staff voted for the fundraisers who they felt went to the most extraordinary lengths to raise money. Two stood out and APF is delighted to recognise both as shining examples of fantastic fundraisers in 2019.

Linda, who has PF and is registered blind, organised an amazing fundraiser in Liverpool. The charity night in February 2019 included a raffle, auction and plenty of dancing - raising over £2,000 - and this inspirational lady is doing it all again in 2020.



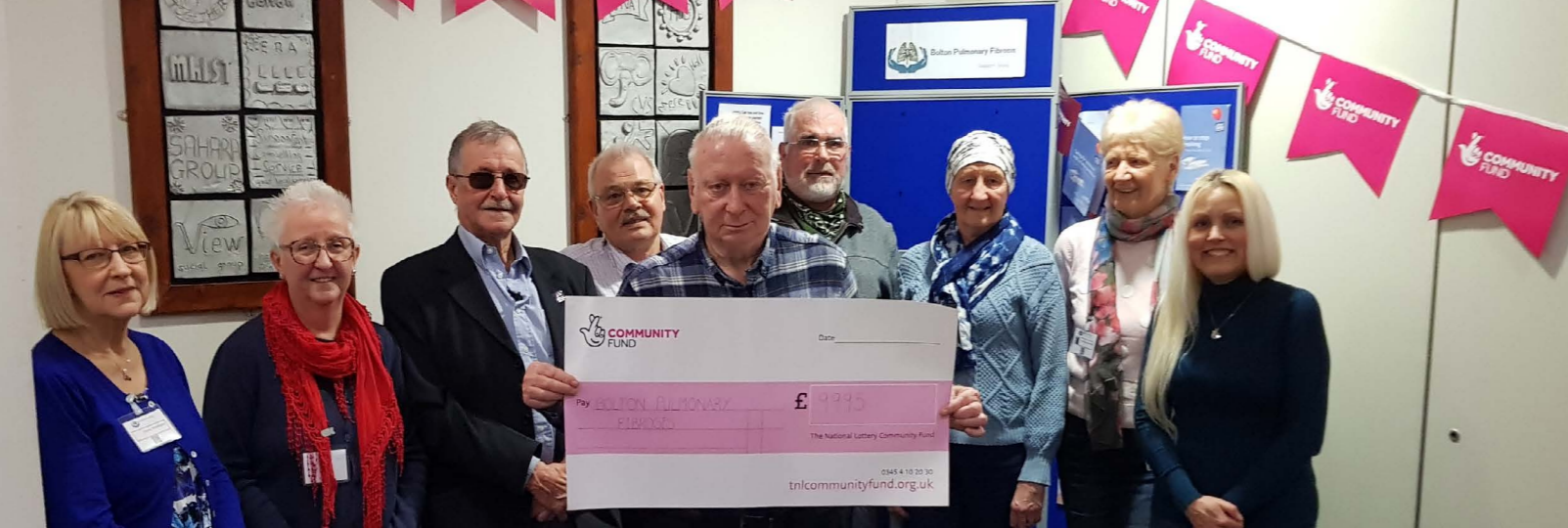
Rebecca wrote to tell us about her 13-year-old sister Eleanor. They lost grandad Bernard when Eleanor was just 11 years old. Since then she secretly squirrelled away two years' worth of birthday and Christmas money, and donated £100 to APF in her grandad's name.

Thanks so much to these two amazing people and the other hundreds of fundraisers without whom we could not support more patients and carers than ever.

We're still here!

Whilst the APF fundraising team are currently working from home for the foreseeable future, we are still on hand to support you and help plan new and innovative ways to raise much needed funds. If you are looking for ideas or have some of your own to share, please do email us at fundraising@actionpf.org





Grab a grant!

APF is eternally grateful for all the fundraising Support Groups do for us across the country. But have you ever thought of raising some funds for yourself? Steve Milward of the Bolton Support Group has had great success with the National Lottery Fund. Here he shares his story.

“We hold our monthly meetings at Bolton CVS which holds various courses throughout the year on how to apply and obtain funding. I came across an introduction to applying for a National Lottery Community Grant and myself and another member of the group decided to go along.

“The talk was given by a local representative of the National Lottery Community Grant team. She was very keen to allay our fears that applying for Lottery Funding was a long and drawn out task with complicated forms and very little chance of success. We were very pleasantly surprised how simple and straightforward the whole process was - all completed online at www.tnlcommunityfund.org.uk.

“We were told that 7 out of 10 of applications for grants of up to £10,000 were successful. One lady at the meeting said that her organisation had applied for the past three years and had been successful every time.

“There are strict criteria and requirements, but no more complex than applying for a community account at a bank. You need to give a clear and concise outline of your project, who would benefit from it, where it would take place and how long it would run for.

“The online form has lots of useful prompts and help sections to assist you in completing the form, and I found the whole process very simple and straight forward. The website keeps a record of when the section is complete, so there is very little chance of submitting an incomplete application. You also have to submit a detailed list of all your costings, such as room hire, printing and so on.

“We received an email to say that the panel were very impressed with our project and that the money would be deposited into our back account in the next couple of weeks. This was nine weeks after we submitted our application. I would encourage anyone thinking of applying for a National Lottery Community Grant to do so, it is a painless straightforward procedure. I would have no hesitation in applying again.”

If anyone has any questions Steve is happy to help – just email steve@boltonpulmonaryfibrosis.org or call 01204 397804. And why not check out your own local CVS to see what support they can offer? Many local councils also offer small grants to health related groups, so it's worth looking into this too. Good luck!

Q and A with the professionals

The Coronavirus pandemic is raising many questions, particularly for those with lung disease. It is a fast-moving situation and we will keep you up-to-date with any new information and advice as we get it on our information hub on the APF website.

We've been listening to your concerns and have come up with a list of questions which you can find on the hub. APF's medical trustees and leading respiratory nurses have answered the questions, covering everything from the availability of drugs and oxygen to what will happen if you experience an exacerbation.

Here are some of the key Q and As at the time of writing in April. Visit the website for the full and up to date list.

What to do if I show symptoms?

If you think you have symptoms of coronavirus call NHS 111. Do not visit your specialist hospital or GP surgery without an appointment.

If you are showing mild symptoms including a fever and cough, continue with your anti-fibrotics and take paracetamol for fever. If symptoms progress or you become increasingly breathless call NHS 111.

Pulmonary fibrosis is not mentioned in the list of conditions of extremely vulnerable people. What should I do?

All ILD patients are now included in the list under category 4: people with rare diseases. We strongly recommend all PF patients to consider themselves to be extremely vulnerable and should be shielding for 12 weeks. This is especially the case if you are on immunosuppressant drugs (eg. mycophenolate mofetil, azathioprine, methotrexate) or anti-fibrotic drugs (pirfenidone and nintedanib).

How can I get assistance with foods and medicines?

If you think you might need help getting deliveries of essential supplies like food or medicines try your local council or community group. We encourage you to register online for government support.

Ask family, friends and neighbours to support you, and use online services. If this is not possible, then the public sector, business, charities, and the general public are gearing up to help those advised to stay at home.

If you receive support from health and social care organisations, this will continue as normal. Your health or social care provider will be asked to take additional precautions to make sure that you are protected.

I'm worried I won't be able to get hold of my prescriptions or oxygen

There are currently no issues with the supply of drugs to fulfil prescriptions or home oxygen. The companies producing the two anti-fibrotic drugs have assured the European IPD Federation (EU-IPFF) and APF that supplies will continue uninterrupted.

Medications for other conditions should be requested in the usual way and will be sent to your nominated pharmacy. With regards to oxygen, you can speak to your supplier for reassurance and the latest information.



Kevin Fitzgerald – IPF advocate and APF champion



Many of you will know Kevin Fitzgerald, a powerful advocate for people with idiopathic pulmonary fibrosis and a dedicated supporter of APF. We asked Kevin to share his journey with IPF for our newsletter. He wrote a fascinating account of life with the disease both here and in the US, where he lived for many years.

Sadly, Kevin passed away a few days before this newsletter was completed. Generously, his wife Teri has allowed us to publish his story. Here is her tribute to a remarkable husband, father and grandfather and Kevin's story.

"It is with extreme sadness I have to report that Kevin passed away from IPF. The journey was hard but he fought with every ounce of strength until the very end."

"When he was first diagnosed, he quickly transitioned his life's work to champion his fellow IPF comrades. He was ready, willing, and extremely able to communicate with everyone to raise awareness and funds to help find a cure. He built a community @IPFAdvocate on both Twitter and Facebook. Our lovely daughters, Samantha, Vanessa, and Jackie were all living in London – all Kevin wanted to do was to be with his children and new grandchild. As soon as we arrived, he organised a walk in Hyde Park for APF."

"I would be remiss if I did not thank the countless NHS doctors, nurses and staff at the Royal Brompton Hospital where Kevin received the best of care. When the doctor called to speak to me he said RBH cared for him deeply - he was a champion patient and advocate, as well as a part of the support group. He was such a positive influence for many in the same situation and it was a loss for RBH as well."

"Kevin was only getting started. He wanted to help others, raise money and do whatever he could to help find a cure. He had so much more to give, and our girls and I will continue the fight in his name."

"We will truly miss @IPFAdvocate but I am sure he is smiling wherever he is, knowing his work will continue through his family."

Kevin's story

"I was born in London but lived in America for many decades. In the summer of 2018, I began to get a bit breathless when walking uphill or going upstairs. I went to my GP and was given antibiotics and later an inhaler which unfortunately did nothing.

"My wife Teri found a consultant and he put me through a number of tests including X-rays, CT scans and blood analyses. Ultimately, I had a lung biopsy which resulted in my IPF diagnosis. I was put on Nintedanib and attended pulmonary rehab at the medical centre, which involved both supervised physical exercise and educational sessions, which were exceptionally helpful.

"I know that the prolonged time for a correct diagnosis is what many have complained about - it's no different in America. It took seven months from my first medical visit to get the correct diagnosis."

The US versus the UK

"Unlike the NHS, in America healthcare is provided by private insurance companies made available through your employer. As a result, if you are unemployed you simply have no insurance. Larger companies (like the one I worked for), have good but expensive plans. There are a number of costs which the employee must pay:

- a monthly insurance premium
- a deductible amount where the insurance company doesn't pay until you pay a certain amount first
- a co-pay where you pay 20% of all bills.

"My IPF reduced my energy and I decided to retire and move back to the UK. We arrived in London in June 2019 and thanks to our daughter Vanessa, found a flat near them and a wonderful GP. I had a list of all my medications and was able to replace them quickly - except for Nintedanib. Fortunately, we connected with the exceptional ILD team at the Royal Brompton Hospital. As a UK citizen and over 65, I was fully covered - an unbelievably pleasant surprise!"

Living with IPF

"As many of you will know, living with IPF has its mental challenges, but by focusing on the here and now I keep a positive attitude. Since none of us knows what tomorrow brings, there isn't much point in worrying about it – that could rob us of our time now. Likewise, focusing on the past and how we used to be is pointless as we cannot change it. For me, I'm grateful for each day, and enjoy my family, including our one-year-old granddaughter who gives us much joy."



"Following up on my pulmonary rehab, I have maintained an exercise regimen (strength and walking) which raises my energy and keeps my attitude positive. I carefully manage side effects of Nintedanib by eating a good amount of food at breakfast and dinner - starches seem to reduce the side effects. I need oxygen when I'm walking outside and, in combination with my ever-present pulse oximeter, this helps me manage my energy and breathing.

"A huge help is my participation in our support group at the Royal Brompton. Not only do I get great information but sitting with people with similar conditions helps me not to feel alone."

IPF Advocate

"After researching the available information about IPF, it became clear that raising awareness was very important. Since I'm active on Twitter and Facebook, I formed IPF Advocate – a non-profit organisation dedicated to raising awareness and encouraging donations to APF.

"I chose APF since they are a patient and caregiver-centred charity. During Pulmonary Fibrosis Awareness Month last year, I organised a 'Walk for the Cure' and raised funds. Increasing awareness helps drive much-needed contributions for research and patient support, and I'm glad to do my bit."



Health Tips - managing anxiety and worry

There can't be many people who aren't becoming worried and anxious at the moment. It's absolutely normal but there are things you can do to help yourself.

Postpone the worry. Instead of engaging with your anxiety right now, try postponing it – and setting aside 30 minutes at the end of the day for worrying. It can feel like an odd thing to do at first, but it will allow you to control your anxiety instead of the other way around.

Plan a new routine. The best routines involve a balance between pleasure, achievement and staying connected to others. The lockdown means many of our normal routines and activities are changing. But from chatting to family on a video call to cooking a new recipe, there are plenty of things we can do to find a balance.

Connect with friends and family. Chatting to those you love will improve your mood. Don't be afraid to be honest about how you're feeling so you can work through the difficult times together.

Be present. Our minds have a tendency to ruminate on the past, or fast-forward to the future, sometimes in a negative way. Mindfulness – focussing on the present moment – can help us calm down.



You could also practise the **APPLE** technique from Anxiety UK (anxietyuk.org.uk):

Acknowledge – Notice and acknowledge the uncertainty as it comes to mind.

Pause – Don't react as you normally do. Don't react at all. Just pause and breathe.

Pull back – Tell yourself this is just the worry talking, and that this apparent need for certainty is not helpful and not necessary. Don't believe everything you think. Thoughts are not statements or facts.

Let go – Let go of the thought or feeling. It will pass. You don't have to respond to negative feelings. You might imagine them floating away in a bubble or on a cloud.

Explore – Explore the present moment because right now all is well. Look around and notice what you see, what you hear, what you can touch, what you can smell. Then shift your attention to something else – on what you need to do, on what you were doing before you noticed the worry, or do something else – mindfully with your full attention.

For links to useful resources visit our website www.actionpulmonaryfibrosis.org/coronavirus/managing-anxiety-and-worry

Research news



As APF celebrates the first exciting developments from research funded through the Mike Bray Fellowship Award (see front page) we take a look at more research news from APF Chair Steve Jones.



Steve with the Manchester cough team

It is estimated that 70% of people with PF suffer from a persistent, often debilitating cough. For many people, it is so bad they give up work and isolate themselves from friends and relatives.

“In my case,” says Steve, “I initially went to see my GP because of a persistent, ticklish cough. After a CT scan and other tests, I was diagnosed with PF, two years before I started to become breathless. The cough stayed with me but became more productive and more difficult to ignore. It was very unpleasant.”

As patients will know from their doctors, there's little to be done for people with 'PF cough'. Mucolytics, which make the sputum easier to move, can help, but there is little else available. To raise awareness of PF cough, APF has become a member of the national task force Action on Cough. It aims to:

- raise awareness of chronic cough among health care professionals and the public
- encourage research into the cases and treatments for chronic cough.



Belfast
Hull – Castle Hill
Liverpool - Aintree
London UCLH
London - Brompton
Manchester
Newcastle
Norwich
Nottingham
Papworth
Southampton (not yet recruiting)

Edinburgh
Hull – Castle Hill
Leicester
Liverpool - Aintree
London - Brompton
Manchester
Nottingham
Papworth
Southampton

If you are an IPF patient and are interested in taking part in either of these trials, talk to your respiratory consultant. The list of sites is shown above. If you have any further questions, we'd be pleased to help. Please contact info@actionpf.org

Participants in the task force include healthcare professionals such as Professor Surinder Biring (King's College Hospital, London) and Professor Jackie Smith (Manchester), and patient representatives. Action on Cough focuses on chronic cough related to specific diseases, and cough caused by neuro-pathological problems.

Although there are currently no therapies for PF cough, pharmaceutical companies are developing possible medicines to alleviate it. Two of these are currently undergoing clinical trials in the UK.

A Californian company, Respiant, is testing a repurposed asthma drug – cromolyn sodium – in a multi-country trial (the SCENIC trial). Another US firm, Trevi Therapeutics, is conducting a safety and tolerability trial of the drug nalbuphine, which targets the nervous system (the CANAL trial).

The two trials should have completed by 2021 but have been put on hold because of coronavirus. If successful, the treatments would need to be tested in further clinical trials. It's a long but necessary process!



Download our Medical Information Form

With the advent of the coronavirus, we know that it is important that any emergency medical staff you may come into contact with know as much as possible about pulmonary fibrosis and your particular situation.

We have therefore published a Patient Medical Information Form which you can download from our website – www.actionpulmonaryfibrosis.org/medical-information-form – and fill in with your personal details. You will be able to list the drugs you take, your oxygen needs and other information which will help emergency teams if you need treatment for Covid-19.

We would urge you to download and fill in this form and keep it with your most recent hospital letter to give to any emergency personnel.

Staying in touch with Action for Pulmonary Fibrosis

We would like to keep in touch with the information you want to receive, in the way you prefer. Please tick the boxes to let us know what updates you would like to receive and how:

APF Newsletter including news on the latest research, support for you or a loved one and fundraising

Updates on fundraising events you can get involved with

Campaigning information and how you can get involved

Information on ways to donate to APF

Would you prefer to be contacted by:

Email Post Telephone

Name _____ Address _____

Email _____ Phone _____

Please return this form to: Freepost ACTION FOR PULMONARY FIBROSIS (no other address required).

If you would like to sign up to our newsletter electronically, please visit www.actionpulmonaryfibrosis.org
You can opt out of receiving information at any time by emailing optout@actionpf.org

Contact Us

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www.actionpulmonaryfibrosis.org
facebook.com/actionpulmonaryfibrosis
twitter.com/actionpfcharity

Email: info@actionpf.org

Support Line: 01223 785 725

Newsletter: If you have a story to share or feedback on this issue, email debbie@djprm.co.uk or call 07498 056979

